

# BMJ Open 'Managing scarcity' – a qualitative study on volunteer-based healthcare for chronically ill, uninsured migrants in Berlin, Germany

Charlotte Linke, Christoph Heintze, Felix Holzinger

**To cite:** Linke C, Heintze C, Holzinger F. 'Managing scarcity' – a qualitative study on volunteer-based healthcare for chronically ill, uninsured migrants in Berlin, Germany. *BMJ Open* 2019;9:e025018. doi:10.1136/bmjopen-2018-025018

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2018-025018>).

Received 26 June 2018

Revised 14 January 2019

Accepted 26 February 2019



© Author(s) (or their employer(s)) 2019. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Institute of General Practice, Berlin, Germany

## Correspondence to

Dr Felix Holzinger;  
[felix.holzinger@charite.de](mailto:felix.holzinger@charite.de)

## ABSTRACT

**Objectives** In Germany, healthcare for people lacking legal residency status and European Union citizens without health insurance is often provided by non-governmental organisations. Scientific studies assessing the situation of the patients with chronic diseases in this context are scarce. We aimed to characterise medical care for chronically ill migrants without health insurance and outline its possibilities and limitations from the treating physicians' perspective.

**Design** Qualitative semi-structured interviews; qualitative content analysis.

**Setting** Organisations and facilities providing healthcare for uninsured migrants: free clinics, medical practices and public health services.

**Participants** 14 physicians working regularly in healthcare for uninsured migrants.

**Results** Delayed contact to the healthcare system was frequently addressed in the interviews. Care was described as constrained by a scarcity of resources that often impedes adequate treatment for many conditions, most pronounced in the case of oncological diseases or chronic viral infections (HIV, hepatitis). For other chronic conditions such as cardiovascular diseases or diabetes, some diagnostics and basic medications were described as partially available, while management of complications or rehabilitative measures are frequently unfeasible. For the patients with mental health problems, attainability of psychotherapeutic treatment is reported as severely limited. Care is predominantly described as fragmented with limitations to information flow and continuity. Which level of care a patient receives appears to depend markedly on the respective non-governmental organisation and the individual commitment, subjective decisions and personal connections of the treating physician.

**Conclusions** Restrictions in medical care for uninsured migrants have even more impact on chronically ill patients. Volunteer-based care often constitutes an inadequate compensation for regular access to the healthcare system, as it is strongly influenced by the limitation of its resources and its arbitrariness.

## INTRODUCTION

In the United Nations Covenant on Economic, Social and Cultural Rights, 166 countries have committed to ensure 'the creation of

## Strengths and limitations of this study

- The comprehensive sample includes physicians from major non-governmental organisations providing volunteer care, state public health services and a number of purposively selected individual practices.
- Qualitative methods allow for profound, detailed insights into the care situation for a marginalised and vulnerable patient population.
- Semi-structured interviews are well-suited to balance interviewees' freedom to voice their views and achieve a degree of comparability between statements.
- Transferability of study results to other settings may be limited, particularly due to divergent legal and financial circumstances.
- As we did exclusively conduct provider interviews, the patient perspective is only reflected by second-hand accounts and remains to be explored in further studies.

conditions which would assure to all medical service and medical attention in the event of sickness',<sup>1</sup> among them all nations of the European Union (EU). However, many countries – including Germany – fall short of the declared ambition of access to healthcare for all. This is especially true in the case of undocumented migrants.<sup>2</sup> The Platform for International Cooperation on Undocumented Migrants defines undocumented migrants as 'persons without residence permit authorising them to regularly stay in the country of destination'.<sup>3</sup> This includes people who overstayed their visa, rejected asylum seekers and people who entered the country illegally.<sup>4</sup>

In Germany, the number of migrants without legal residence permit was estimated in 2014 to be between 180 000 and 520 000 people,<sup>5</sup> with an upward tendency.<sup>6</sup> Having no legal status often leads to precarious working and living conditions, aggravated by fear of detection and deportation.<sup>7</sup> Officially,

healthcare for undocumented migrants is ascertained by German asylum-seekers law, granting access to treatment for acute or painful diseases.<sup>8</sup> As state institutions are legally required to report people without legal residency status to immigration authorities, undocumented migrants risk deportation if they contact social welfare authorities to make use of their formal right to healthcare.<sup>9</sup> This is also the case with hospital emergency department visits, as police may be contacted if migrants cannot provide any identification.<sup>10</sup>

Non-governmental organisations (NGOs) and public health services also report an increase of patients originating from the comparatively 'new' EU member states Romania and Bulgaria, lacking access to health insurance despite having right of residence.<sup>11,12</sup> EU citizens can enter German health insurance only if they are employed or entitled to welfare benefits, which does not apply in some cases. These migrants often face economic precarity and exclusion,<sup>13</sup> despite their situation not being complicated by a constant threat of being deported. It is important to know in this context that the legal situation of EU citizens in regard to healthcare entitlement has been made more difficult by a number of recent legislative changes, like for example a 2017 law excluding EU migrants without employment and less than five years of domestic residence from social welfare benefits, and thus from entitlement to enter German statutory health insurance.<sup>14</sup>

In consequence, despite different legal contexts, both undocumented migrants and EU citizens without health insurance depend on parallel care structures in case of illness, being denied access to regular healthcare. In Berlin, state public health services only offer prenatal care and treatment for tuberculosis and a number of sexually transmitted infections (STI). All other medical care for uninsured migrants is basically left to a number of NGOs providing free clinics or arranging anonymous consultations at volunteering general practitioner (GP) and specialist practices. They are primarily funded by donations.

This situation is considered especially deleterious for chronically ill people: with financial and language issues constituting further access barriers,<sup>15</sup> these particularly vulnerable patients may wait until there is no other option before consulting any healthcare services at all.<sup>7,16</sup> The term 'chronic illness' is used very differently in the literature.<sup>17</sup> The presence of the illness over a longer period of time and the need for ongoing medical care are commonly used defining features.<sup>18,19</sup> Besides 'classic' chronic illnesses like diabetes mellitus or hypertension, a number of communicable diseases (eg, HIV, hepatitis or tuberculosis) and long-term or recurrent mental conditions also fit these criteria. As care provision by NGOs and volunteers is often fragmented and informal, corresponding research is scarce. This study aims to shed a light on the possibilities and limitations of medical care for chronically ill, uninsured migrants in the metropolitan setting of Berlin, Germany. Concerning the concept of 'chronic illness', we decided for a broad approach

considering all diseases requiring regular care for an extended period of time.

## METHODS

### Study design, sampling and setting

Study design and results are reported in compliance with the Standards for Reporting Qualitative Research criteria.<sup>20</sup> Due to the exploratory nature of the research question, a qualitative study design was chosen. As a first step, it seemed prudent to evaluate care provision in interviews with providers in the volunteer care system, as access to the patients is difficult and impeded by language barriers. Our research team consisted of a doctoral student (CL) and two GPs experienced in qualitative research (FH, CH). Qualitative semi-structured interviews were conducted with physicians providing care for uninsured migrants in the NGO system and government public health services after compiling a comprehensive list of such providers. One of the researchers (CL) was able to provide valuable information about key organisations and structures of this parallel care sector, as she had been volunteering for an NGO arranging medical consultations for uninsured migrants and was also working in social counselling for homeless EU citizens. Thus, we were also able to get into contact with individual physicians' practices involved in volunteer healthcare. Sampling of interviewees was purposive, aimed at a heterogeneous group of participants: we aimed to include GPs as well as specialists, interviewees of female and male gender and different age groups. However, this strategy could be mainly applied to the physicians from individual practices, as these were contacted directly. NGOs and public health services were contacted via e-mail and asked to forward an information letter to their physicians, so we had to rely on the organisations to approach their team with the request to volunteer for the study. On the organisation level, we strived to cover the whole spectrum of NGOs engaged in local migrant healthcare. In addition to organisations focusing explicitly at these patients, we also included some purposefully selected clinics providing care to the homeless, as we knew from our research of the field and conversations with personal contacts that a relevant number of uninsured migrants would consult these for treatment, even if they were not homeless. The response rate (proportion of inquiries resulting in interviews) was 57% (4/7) for organisations and 47% (8/17) for individual practices. Reasons given for non-response were 'we do not treat a relevant number' (two organisations, one practice) and 'we do not have the capacities for an interview' (one organisation, two practices). Six practices did not provide an explanation.

The setting of metropolitan Berlin is deemed exemplary for other urban European contexts. With more than 3.5 million inhabitants, Berlin is the most populated city in Germany as well as its capital. Berlin's per capita gross domestic product ranges sub-average in national comparison.<sup>21</sup>

**Table 1** Examples of questions in the interview guideline (selected)**What does your work with uninsured migrants normally look like?****Please tell me about the last chronically ill patient who consulted you**

Focuses	<ul style="list-style-type: none"> <li>▶ Country of origin and residency status</li> <li>▶ Disease(s)</li> <li>▶ Waiting time until seeking advice</li> <li>▶ Necessary treatment</li> <li>▶ Current treatment possibilities</li> <li>▶ Long-term perspective</li> </ul>
---------	--

**Could you tell me about a chronically ill patient who remained a special memory for you?**

Focuses	<ul style="list-style-type: none"> <li>▶ Country of origin and residency status</li> <li>▶ Disease(s)</li> <li>▶ Waiting time until seeking advice</li> <li>▶ Necessary treatment</li> <li>▶ Current treatment possibilities</li> <li>▶ Long-term perspective</li> </ul>
---------	--

**Which chronic diseases do you frequently see in your work?**

Focuses	<ul style="list-style-type: none"> <li>▶ Non-communicable/communicable/mental</li> <li>▶ Severity and stage of disease at presentation</li> <li>▶ Differences in regard to insured patients</li> </ul>
---------	--

**Do you experience any conflicts while working with uninsured migrants?**

Focuses	<ul style="list-style-type: none"> <li>▶ Conflicts between necessities and possibilities of care</li> <li>▶ Conflicts with patients</li> <li>▶ Conflicts with authorities</li> </ul>
---------	--

**Data collection**

Based on literature research,<sup>7 13 15 16</sup> a semi-structured interview guideline was developed (CL, FH, CH), pre-tested and finalised after revision. Issues addressed included status quo of medical care, reasons for consultation, treatment options and barriers, influence of legal status and solution strategies (table 1).

Interviews were centred at the interviewees' personal experience and opinion; any judgement of their testimonials was avoided meticulously. All interviews were conducted by CL between February and September 2015 at the interviewees' workplace, only the respective physician and the interviewer were present.

Demographic data and characteristics of NGO/practice were documented via separate questionnaire. Participants' informed consent to audio-recording, storage and pseudonymised analysis of the interviews was obtained. After the interviews, notes on specific incidents, interview atmosphere and difficult parts were taken; these were used for contextualisation. Interviews were concluded once no further new themes emerged.

**Data analysis**

Interviews were audio-recorded and transcribed verbatim using the software f4 transcript.<sup>22</sup> During transcription, interviewees were assigned codes for pseudonymisation, personal or institutional identifiers were removed.

Qualitative content analysis based on the principles of Mayring and Steigleder<sup>23 24</sup> was performed. Content analysis is especially suitable for describing and understanding social reality and was therefore favoured over

other possible approaches – like for example grounded theory – focusing more on open exploration and theory generation.<sup>25</sup> The category system was developed in a combined inductive-deductive procedure. A first set of deductive categories was based on themes derived from scientific literature on the topic<sup>7 13 15 16</sup> and the theoretical framework that already influenced the interview guide. Transcripts were then structured into segments according to content in a first coding cycle, and a second set of categories was derived from the material in an inductive process.<sup>24</sup> Part of the material was coded separately by members of the research team (CL, FH, CH) and subsequently discussed. Category sets were then combined; the resulting system was reviewed for overlap or ambiguity and revised. Subsequently, categories were further compartmentalised into sub-categories according to different manifestations of themes raised. Categories were aimed to be mutually exclusive, unidimensional and exhaustive.<sup>26</sup> A final coding guideline with anchor examples and demarcation rules was developed (see excerpt in table 2). This was repeatedly reflected within the team, controversial text passages were discussed. The whole of the material was finally re-coded according to the coding guideline.

Notes on context taken during the interviews proved helpful in some instances for coding in cases of uncertainty concerning the understanding of individual statements, but in fact, this was not very frequently the case. For quality assurance and in order to limit the conceivable impact of presuppositions and implicit expectations

**Table 2** Example of the coding guideline

Category	Actual situation of care	
1. Subcategory	Continuity of care	
Definition	All statements regarding possibility/lack of possibility of continuous medical care, with reasons (if stated)	
2. Subcategory	Continuous care not possible	Continuous care possible
Additional rule	Also code here: statements concerning lost contact with the patients	
Anchor example	<i>'Usually, I see them maybe once again, but not regularly.'</i> (#3_26)	<i>'Our experience is really, that a lot of people appreciate our offer, because they know, we are here every Wednesday, and the door is open and they can come back again and again.'</i> (#1_50)

that might influence interpretation,<sup>27</sup> the coding process was regularly discussed in in-house qualitative methods workshops that included researchers with different scientific backgrounds. The majority of participants in these regular sessions were not directly involved in the study, thus complementing analysis with a supposedly more impartial view on the material and the topic of volunteer healthcare.

Main categories were 'actual situation of care', 'influencing factors', 'access to regular care' and 'solution strategies'. For this paper, we focused mainly on the 'actual situation' and the 'influencing factors'. Subcategories were essential to organise the content and discern patterns and focus areas. However, coverage of the entirety of subcategories in the outline of results would have negatively impacted readability. The subsequent results presentation is consequently structured according to categories of higher hierarchical levels, while subcategories implicitly guide focus and direction of the summary. Quotations were translated into English from the original German by CL and FH.

### Patient and public involvement

Patients were not involved in the design and conduct of the study. Participants were asked whether they would like to receive a report on the study's findings. Study results will be disseminated to interviewees who desired such.

## RESULTS

### Participants and interviews

A total of 14 physicians were interviewed, five GPs and nine with other specialties. Five of them worked for a free clinic, eight in a medical practice, and one for the public health service. Six of the physicians in medical practices cooperated with an NGO that coordinates medical consultations for uninsured migrants in volunteer practices, one with public health services. Table 3 shows the characteristics of the sample in detail. Average interview length was ~45 min (minimum: 25 min, maximum: 60 min).

### Actual situation of care

A majority of the interviewees emphasised that many chronically ill, uninsured migrants seen in their facility had not sought or received any medical care for a long time. Complications and sequelae of chronic diseases were commonly seen. The scope of healthcare that could be provided varied widely between different free clinics and medical practices, depending on various determinants. Besides organisational and financial issues, type of disease emerged as an important distinguishing factor.

Interviewees reported that basic diagnostic investigations for cardiovascular diseases like an ECG or laboratory testing could be performed in a substantial number of facilities. Some specialist practices could even offer long-term ECG or blood-pressure monitoring. While most physicians stated that long-term treatment with cardiovascular medications was possible, some described important limitations, like necessity to change medications depending on availability or not being able to provide platelet aggregation inhibitors regularly for financial reasons. Surgical interventions were mostly limited to emergencies:

*However, there are diseases, where you know, it will inevitably happen, if nothing is done somehow preventively, for example bypass surgery [...] and the patient slowly gets angina pectoris, and in this case it's not an emergency [...]. And in the end, there is no treatment, because nobody can pay for it. (#2\_61) GP, free clinic*

For diabetic patients, most doctors stated that they were able to offer blood glucose and haemoglobin A1c measurements and treatment with oral antidiabetics. Only one physician described the provision of long-term insulin therapy as possible within the structures of his NGO. Care for the patients with advanced diabetes complications was also difficult for lack of access to therapeutical appliances and measures of rehabilitation.

Testing for STI (including HIV, hepatitis B and C) and tuberculosis is provided by public health services, and doctors reported to frequently refer such patients there. However, STI treatment in these government-financed



**Table 3** Characteristics of participating physicians

Type of facility	Medical practices	Free clinics*	Public health service
Medical specialties	Infectiologist 2 GPs† GP/Psychotherapist‡ Cardiologist† Pulmonologist‡ Neurologist‡	GP/Radiologist 2 Internists Surgeon GP	Gynaecologist Pulmonologist‡
Gender			
F	4	1	2
M	3	4	0
Age range			
20–30	1	0	0
30–40	0	1	1
40–50	2	0	1
50–60	2	2	0
60–70	2	0	0
70–80	0	1	0
Years of work with uninsured migrants			
Mean	8.6	3.4	1.5
Median	5	1	1.5
Range	2–23	1–11	1–2

\*Name of NGO/affiliation of clinics not listed for reasons of data protection and anonymity.

†Cooperation with coordinating NGO.

‡Medical practice, cooperation with public health services.

GP, general practitioner; NGO, non-governmental organisation.

clinics is limited to short-term therapy (eg, antibiotic). Long-term treatment for HIV or hepatitis B and C was predominantly described as not feasible:

*With those drugs for HIV or hepatitis, they are so horrendously expensive. Sure, from time to time, I have some drugs in my locker, which a patient was prescribed, but then didn't take, and when you have such drugs, you can of course use them, but this is only for a month or two, and that is quite unsatisfactory. (#11\_49) Infectiologist, medical practice*

The situation for tuberculosis care was pictured as different: treatment and care for concomitant illnesses are covered by public health services until the disease is under control.

Not all doctors had firsthand experience with uninsured patients with oncological diseases, but those who did described them as frequently presenting in advanced stages:

*Like for example, this Vietnamese woman, who came here, and spat blood, and I did an ultrasound and the liver metastases already jumped out at me, and at first we didn't know what to do. (#2\_51) GP, free clinic*

As all treatment options for oncological diseases are expensive, most doctors described cancer treatment in uninsured patients as virtually impossible. An option of last resort mentioned by some interviewees was to support

the patients in applying for a temporary residence permit for humanitarian reasons.

None of the interviewees was a psychiatrist, only one GP had a psychotherapy specialisation. Some physicians described that they would usually try to refer the patients with severe mental health problems to psychiatrists personally known to them. In case of a specialist prescription, a few of the NGOs had the policy to hand out respective psychopharmacological medications. Psychotherapeutic care was more difficult to realise, with language barriers posing additional challenges. The interviewed psychotherapist described the difficulties in treating illegalised patients with post-traumatic stress disorder (PTSD):

*The treatment of people with PTSD in such a bad legal situation is always a bit like squaring the circle, because the actual aim is to understand that the horrors are over, but life goes on [...]. However, in fact, this is not true at all, when you always think, have to think, that you will be deported. (#13\_26) GP, Psychotherapist, medical practice*

### Fragmentation and lack of continuity of care

Coordinated care involving more than one medical specialty was frequently outlined as difficult. As the patients did often not bring along any information about preceding treatments and language barriers impeded detailed history taking, making contact with colleagues involved in previous care was described as

tough. For the same reasons, physicians often were not informed about the results of later consultations elsewhere. Arranging hospitalisations, especially in non-emergency situations, often required a functioning network of personal contacts and was described as frequently time-consuming and frustrating.

*Then I sent him, with desperately sad letters to the dear colleagues in the hospitals, begging on my knees, to admit this man and perform some investigations, him being a man of 34 years with blood pressure levels of 200 [...]. Horrible. (#5\_125) Surgeon, free clinic*

Most of the specialists and some of the GPs in individual medical practices reported seeing a majority of their uninsured patients only once.

*Many actually don't return, I know, they are chronically ill, regularly in need of something, but I don't know exactly where they go afterwards. (#9\_19) GP, medical practice*

Physicians from the free clinics reported seeing a number of their chronically ill patients regularly in their institution, especially for repeat prescriptions. However, as the physicians usually worked on a voluntary hourly basis in their spare time, the patients commonly would not meet the same doctor again.

### Influence of physicians' views and commitment

Some interviewees stressed that especially chronically ill, uninsured patients remain in constant dependency to the respective NGO and their physicians, as they are not legally entitled to a certain level of care. It was mentioned in this context that the care they receive frequently depended on subjective decisions, influenced by the personal ethical stance of the individual doctor.

*They notice, when they come repeatedly with chronic diseases, that every single physician here has his own ethical views about how to proceed. And from one they get more, from another one they get less. (#4\_91) Internist, free clinic*

Furthermore, the interviews showed noticeable differences in physicians' respective dedication to search for solutions in situations without clear, easy options. This is illustrated by three cases of the patients with breast cancer related by different interviewees; two of them concluded that – while frustrating – there was nothing they could do, as this quote shows exemplarily:

*There was a woman, she was from Bulgaria, she had a big breast tumour. And she had been to different hospitals and did not get surgery, because costs were not covered. I had to send her away, too. She was practically discharged without treatment. (#14\_42) GP, free clinic*

For a similar constellation, another physician however described a much more elaborate approach:

*We have a Bulgarian patient at the moment, in her late forties, who has a breast carcinoma. [...] We sent her directly to a hospital, to a breast centre. There she was seen, even had*

*a biopsy. [...] we would have liked to enable an operation here, but this failed due to the costs. So now we organise for her to go back to Bulgaria with support, we pay the outstanding premiums for the health insurance there [...] and we try to contact a hospital in Bulgaria [...] (#8\_15) Internist, free clinic*

These portrayals show that care in individual cases may not only depend on the commitment of the treating physician, but also on her or his personal network of contacts to colleagues, hospitals, social workers, etc. In volunteer structures with limited resources, physicians are constantly forced to make decisions that may challenge their professional ethics.

*Managing scarcity is hard to bear [...] this weighs quite heavily, and causes frustration. (#14\_92) GP, free clinic*

*I think it would be utterly important to initiate a public debate – or make it clear somehow – what many physicians and health workers do on a voluntarily basis, to make a situation bearable, that is actually not bearable. (#1\_105) GP, medical practice*

## DISCUSSION

### Summary of findings

The interviews paint a differentiated picture of medical care for chronically ill, uninsured migrants in the NGO system. Physicians described care as limited by a scarcity of resources that often impedes adequate management of many conditions. Care was predominantly experienced as fragmented and difficult to coordinate with limitations to information flow and care continuity. Which level of care a patient receives seems to depend markedly on the respective NGO, the individual commitment, subjective decisions and personal connections of the treating physician. Physicians face a multitude of ethical dilemmas.

### Strengths and weaknesses

This qualitative study illuminates the current care situation in a parallel care sector characterised by precarity and informal structures. It specifically explores the possibilities and limitations of medical care for chronically ill, uninsured migrants in the setting of an EU metropolis.

Some important limitations apply: First, qualitative research can never claim representativeness in a statistical sense, as samples are small and non-probabilistic. However, as its purpose is to explore and explain rather than to quantify, it is the adequate method to approach a setting often ignored by health services research, as it exists 'in the shadows' of regular healthcare. As not all organisations approached agreed to participate in our study, there remains a certain caveat in regard to representativeness of the field. Additionally, as individual physicians were sampled purposively, the distribution of medical specialties in our sample does very likely not represent the actual proportions of the disciplines of volunteer providers; sampling was rather aimed at displaying the variety of specialties involved and capturing a large spectrum of

perspectives. There might also be physicians or networks active in volunteer healthcare that are not known to us, as this is not an official or regulated care sector. However, we are confident to have achieved a meaningful sample including both physicians from major NGOs active in uninsured migrant healthcare in Berlin, and also a relevant spectrum of potential interview partners on the side of individual volunteer providers. Nevertheless, it would be important to complement the physicians' view by the patients' perspective in a future study.

Transferability to other healthcare systems might be another issue of concern.<sup>28</sup> However, as Germany is by no means the only high-income country that denies undocumented migrants access to – even minimum – healthcare,<sup>4</sup> physicians in other settings will face similar challenges.<sup>29</sup>

### Results in context

The majority of international literature discussed in the following sections focuses on undocumented migrants, as the situation of a growing number of people with legal residency status depending on volunteer-based healthcare is a relatively new phenomenon, resulting from EU enlargement regulations. It was notable that our interviewees did usually not distinguish between uninsured and undocumented migrants. Physicians often stated that they did frequently not ask their patients for detailed information about their status or background at all, as it would not have influenced their treatment in the volunteer setting. However, in some individual cases related in the interviews and presented in the results section of this paper, legal situation was of implicit importance for the care options and outcome, as the example of the Bulgarian cancer patient who could finally achieve insurance status in her country of origin shows. On the other hand, fear of deportation as a complicating factor is special to the situation of migrants without official residency status. As might be expected, interviews insinuated that EU citizenship offers more legal leeway for arranging adequate care in some circumstances, but distinctions in residency status were not explicitly voiced as a central influencing factor for care provision.

General limitations in care described by our interviewees are in line with preceding studies on medical care for undocumented migrants that have outlined an overall reduced care quality in a variety of settings. Late presentation,<sup>7 16</sup> insufficient and inadequate care,<sup>30</sup> lack of continuity,<sup>31 32</sup> limited availability of medication,<sup>16</sup> complexity of health problems<sup>15</sup> and communication barriers<sup>15 29</sup> are frequently discussed as important influencing factors and likewise reflected in the statements of our interviewees.

Concerning chronic cardiovascular care, a recent study from the Netherlands<sup>33</sup> comparing GPs' practice records of undocumented and documented migrants found that undocumented migrants would consult the GP less frequently, while no difference in medication prescription could be seen. Whereas a direct comparison between this quantitative data and our results is not viable, it is nevertheless interesting that our interviews suggest a

more problematic supply for the German setting. The Netherlands, however, grant undocumented migrants a statutory right to basic healthcare, financed by a fund.<sup>33</sup> We could not identify any other studies that have specifically evaluated the question of cardiovascular care in comparable patient populations.

For diabetes, the problematic constellation of being undocumented and dependent on regular insulin has been thematised previously for the German care environment.<sup>16</sup> Correspondingly, research from the USA indicated that undocumented migrants with diabetes are less likely to regularly see a doctor compared with documented migrants.<sup>34</sup> Facilitating access has been shown to improve health outcomes: a study conducted in two immigration 'sanctuary' areas (San Francisco Bay; Chicago) showed no differences in clinical outcome and healthcare experiences of undocumented and documented migrants with diabetes.<sup>35</sup> This corresponds to findings from a retrospective study in a public hospital in Geneva, Switzerland, enforcing health-equity policies.<sup>36</sup>

Research on uninsured migrants with oncological diseases is scarce. Few case reports from the USA describe the practical and ethical difficulties in end-of-life care for undocumented cancer patients: access limited to acute crises, inaccessibility of hospices and lack of advanced care planning.<sup>37–39</sup> A retrospective analysis of data from a US safety net hospital showed undocumented Hispanic women with breast cancer presenting at a younger age and with more advanced stages of disease. However, in this study, being undocumented was not associated with increased mortality, which might be explained by the fact that these patients had access to all necessary cancer treatment, which markedly differs from the situation of our setting.<sup>40</sup> Applying for a temporary residency status for humanitarian reasons in case of severe illness to gain access to medical care was mentioned by some of our interviewees as an option of last resort. A corresponding case has been discussed by Castañeda. However, she describes that the patient was eventually deported after improvement, even though follow-up treatment was not secured in his country of origin.<sup>41</sup>

While many studies thematise communicable disease incidence in populations of undocumented migrants,<sup>42 43</sup> there is few research on treatment options. As German public health services are obligated by law to treat people with tuberculosis,<sup>44</sup> most of the interviewed physicians in our study reported to usually refer respective patients to these institutions. The special situation of tuberculosis care being accessible to undocumented migrants applies as well for many other countries.<sup>45</sup> However, these regulations are rooted in epidemic control and not based on humanitarian reasons. Concerning other chronic infections, none of the interviewed physicians was able to offer long-term antiretroviral therapy (ART) for HIV positive patients. Germany is one of 14 EU member states without access to ART for undocumented migrants,<sup>46</sup> even though early treatment is effective for reducing HIV transmission, morbidity and mortality.<sup>47 48</sup> Antiviral



therapy for hepatitis is likewise impeded by the required high expenditure.

Existing literature suggests that many undocumented migrants suffer from mental health problems,<sup>31 49</sup> often related to fear of deportation and precarious living conditions.<sup>7 16 50</sup> Conversely, specific services providing mental healthcare for undocumented migrants are relatively rare.<sup>51</sup> The finding of medication-based treatment being easier to achieve than psychotherapeutic treatment was likewise described by the Castañeda study.<sup>16</sup> A study from the Netherlands also found that undocumented people were referred significantly more often to psychiatrists than psychologists, probably because psychologists would not receive any reimbursement for conceivable psychotherapeutic care.<sup>52</sup> For Greece, problems with drug prescription and referrals to mental health institutions due to lack of reimbursement were also described.<sup>53</sup> Both studies mention low consultation rates, frequent presentation of mental illness with somatic symptoms and lack of trust as additional barriers.<sup>32 53</sup>

Concerning the dependencies on the respective care provider, a systematic review of qualitative research on rationing strategies in healthcare has summarised how context-, physician- and patient-related factors influence decision making.<sup>54</sup> Ethnographic research has pointed out how clinical experiences, medical training and narratives on migrant patients additionally influence the physicians' attitudes towards their patients.<sup>55</sup> In voluntary medical care, limitation of resources is much more severe: physicians are obliged to decide how to ration the care they are providing.<sup>41</sup> Therefore, the influence of the physicians' attitude, personal resources and relation to the patient is more pronounced than in regular medical care for insured people. While some of the interviewed physicians struggled to fulfil both their patients' needs and their own professional and ethical aspirations, constantly trying to overcome the limitations of the setting, others were more accepting of these limitations. The dependency of uninsured migrants on their individual physicians' sense of responsibility and the arbitrariness of decisions in settings based on humanitarianism rather than entitlement has been discussed in the context of medical anthropology.<sup>56 57</sup> Our study thus illustrates the magnitude of the resulting differences in medical care.

## CONCLUSIONS

Our results show that volunteer-based healthcare for chronically ill patients – even though it might momentarily alleviate the situation – constitutes only an inadequate substitute for regular access to the healthcare system, being strongly influenced by limitation of resources and a high level of arbitrariness. Shifting the responsibility to NGOs rather than enabling access to regular healthcare puts the patients' health at risk and creates conflicting situations for the treating physicians. In Germany, the situation is more likely to further escalate than to improve, as new legislation – especially regarding

EU citizens – excludes even more people from the regular care system.<sup>14</sup> Ameliorating this situation is a political task that seems overdue, not only from a human rights point of view, but also from a scientific perspective, as study results from other countries<sup>33 35 58</sup> indicate that enabling regular access to healthcare constitutes an important step towards ultimately improving health for undocumented migrants and those without health insurance.

**Acknowledgements** The authors would like to express their thanks to the physicians taking part in our study. We acknowledge support from the German Research Foundation (DFG) and the Open Access Publication Fund of Charité – Universitätsmedizin Berlin.

**Contributors** All authors contributed to study design, development of the interview guideline and sampling strategy. CL conducted and transcribed the interviews and drafted the category system, which was reviewed and edited by FH and CH. CL wrote the first draft of the manuscript, FH critically revised and finalized the article. CH supervised the project. All authors read and approved the final manuscript.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The study was approved by the ethics committee of Charité – Universitätsmedizin Berlin (EA2/010/15). Written informed consent to participation was obtained from all participants.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** No additional data are available.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

## REFERENCES

1. United Nations. International Covenant on Economic, Social and Cultural Rights (ICESCR) - Resolution 2200A (XXI). 16.12.1966. <http://www.ohchr.org/EN/ProfessionalInterest/Pages/ICESCR.aspx> (Accessed 04th Jul 2018).
2. Suess A, Ruiz Pérez I, Ruiz Azarola A, et al. The right of access to health care for undocumented migrants: a revision of comparative analysis in the European context. *Eur J Public Health* 2014;24:712–20.
3. PICUM. Platform for International Cooperation on Undocumented Migrants: Access to health care for undocumented migrants in Europe. 2007 [http://picum.org/Documents/Publi/2007/Access\\_to\\_Health\\_Care\\_for\\_Undocumented\\_Migrants\\_in\\_Europe.pdf](http://picum.org/Documents/Publi/2007/Access_to_Health_Care_for_Undocumented_Migrants_in_Europe.pdf) (Accessed 09th Jan 2019).
4. Cuadra CB. Right of access to health care for undocumented migrants in EU: a comparative study of national policies. *Eur J Public Health* 2012;22:267–71.
5. Vogel D. Update report Germany: Estimated number of irregular foreign residents in Germany 2014. Database on Irregular Migration. 2015 <http://irregular-migration.net/> (Accessed 03rd Jul 2018).
6. Vogel D. Kurzdossier: Umfang und Entwicklung der Zahl der Papierlosen in Deutschland, AbIB – Arbeitspapier 2/2016. Universität Bremen, Fachbereich 12: Erziehungs- und Bildungswissenschaften, Arbeitsbereich Interkulturelle Bildung, 2016.
7. Kuehne A, Huschke S, Bullinger M. Subjective health of undocumented migrants in Germany - a mixed methods approach. *BMC Public Health* 2015;15:926.
8. Asylbewerberleistungsgesetz in der Fassung der Bekanntmachung vom 5. August 1997 (BGBl. I S. 2022), das zuletzt durch Artikel 4 des Gesetzes vom 17. Juli 2017 (BGBl. I S. 2541) geändert worden ist. 2017 <https://www.gesetze-im-internet.de/asylblg/BJNR107410993.html> (Accessed 14th Jul 2018).
9. Aufenthaltsgesetz in der Fassung der Bekanntmachung vom 25. Februar 2008 (BGBl. I S. 162), das zuletzt durch Artikel 1 des



- Gesetzes vom 8. März 2018 (BGBl. I S. 342) geändert worden ist. 2018 [https://www.gesetze-im-internet.de/aufenthg\\_2004/BJNR195010004.html](https://www.gesetze-im-internet.de/aufenthg_2004/BJNR195010004.html) (Accessed 14th Jul 2018).
10. Mylius M. [Hospitalization of Migrants without Health Insurance: An Explorative Study of Hospital Healthcare in Lower Saxony, Berlin and Hamburg]. *Gesundheitswesen* 2016;78:203–8.
  11. Lott EY, Hämmerling C, Mielck A. Health Status of Persons without Health Insurance and of Undocumented Migrants: Analysis of Data from the Malteser Migranten Medizin (MMM) in Munich, Germany. *Gesundheitswesen* 2015;77:143–52.
  12. Schade M, Heudorf U, Tiarks-Jungk P. [The Humanitarian Consultation-hour in Frankfurt am Main: Utilization by Gender, Age, Country of Origin]. *Gesundheitswesen* 2015;77:466–74.
  13. Huschke S. Performing deservingness. Humanitarian health care provision for migrants in Germany. *Soc Sci Med* 2014;120:352–9.
  14. Gesetz zur Regelung von Ansprüchen ausländischer Personen in der Grundsicherung für Arbeitsuchende nach dem SGB II und in der Sozialhilfe nach SGB XII vom 22.12.2016 (BGBl. I S. 3155). 2016 <http://dipbt.bundestag.de/extrakt/ba/WP18/772/77237.html> (Accessed 28th Nov 2018).
  15. Woodward A, Howard N, Wolfers I. Health and access to care for undocumented migrants living in the European Union: a scoping review. *Health Policy Plan* 2014;29:818–30.
  16. Castañeda H. Illegality as risk factor: a survey of unauthorized migrant patients in a Berlin clinic. *Soc Sci Med* 2009;68:1552–60.
  17. Goodman RA, Posner SF, Huang ES, et al. Defining and measuring chronic conditions: imperatives for research, policy, program, and practice. *Prev Chronic Dis* 2013;10:E66.
  18. Hwang W, Weller W, Ireys H, et al. Out-of-pocket medical spending for care of chronic conditions. *Health Aff* 2001;20:267–78.
  19. US Department of Health and Human Services. Multiple chronic conditions — a strategic framework: optimum health and quality of life for individuals with multiple chronic conditions. 2010 [http://www.hhs.gov/ash/initiatives/mcc/mcc\\_framework.pdf](http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf) (Accessed 09th Jan 2019).
  20. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.
  21. Statista GmbH. Bruttoinlandsprodukt (BIP) je Erwerbstätigen in Deutschland nach Bundesländern im Jahr 2017. 2018 <https://de.statista.com/statistik/daten/studie/254144/umfrage/bruttoinlandsprodukt-je-erwerbstaetigen-in-deutschland-nach-bundeslaendern/> (Accessed 15th Apr 2018).
  22. Dresing T, Pehl T. *f4-transkript, File Version 5.4.0.0*, 2015.
  23. Mayring P. Qualitative Content Analysis. *Qual Soc Res* 2000;1:20.
  24. Steigleder S. *Die strukturierende qualitative Inhaltsanalyse im Praxistest: eine konstruktiv kritische Studie zur Auswertungsmethodik von Philipp Mayring*. Marburg: Tectum-Verlag, 2008.
  25. Cho JY, Lee E. Reducing confusion about grounded theory and qualitative content analysis: similarities and differences. *The Qualitative Report* 2014;19:1–20.
  26. Schreier M. *Qualitative content analysis in practice*. London: SAGE Publications, 2012.
  27. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001;358:483–8.
  28. Grit K, den Otter JJ, Spreij A. Access to health care for undocumented migrants: a comparative policy analysis of England and the Netherlands. *J Health Polit Policy Law* 2012;37:37–67.
  29. Dauvin M, Lorant V, Sandhu S, et al. Health care for irregular migrants: pragmatism across Europe: a qualitative study. *BMC Res Notes* 2012;5:99.
  30. Winters M, Rechel B, de Jong L, et al. A systematic review on the use of healthcare services by undocumented migrants in Europe. *BMC Health Serv Res* 2018;18:30.
  31. Schoevers M. "Hiding and Seeking": health problems and problems in accessing health care of undocumented migrants. Nijmegen, Netherlands: Department of Primary and Community Care, Radboud University, 2011.
  32. Teunissen E, Van Bavel E, Van Den Driessen Mareeuw F, et al. Mental health problems of undocumented migrants in the Netherlands: A qualitative exploration of recognition, recording, and treatment by general practitioners. *Scand J Prim Health Care* 2015;33:82–90.
  33. van de Sande JSO, van den Muijsenbergh M. Undocumented and documented migrants with chronic diseases in Family Practice in the Netherlands. *Fam Pract* 2017;34:649–55.
  34. Do EK, Matsuyama RK. Healthcare utilization among Hispanic immigrants with diabetes: investigating the effect of US documentation status. *J Immigr Minor Health* 2014;16:189–94.
  35. Iten AE, Jacobs EA, Lahiff M, et al. Undocumented immigration status and diabetes care among Mexican immigrants in two immigration "sanctuary" areas. *J Immigr Minor Health* 2014;16:229–38.
  36. Jackson Y, Lozano Becerra JC, Carpentier M. Quality of diabetes care and health insurance coverage: a retrospective study in an outpatient academic public hospital in Switzerland. *BMC Health Serv Res* 2016;16:540.
  37. Metchnikoff C, Naughton G, Periyakoil VS. End-of-life care for unauthorized immigrants in the U.S. *J Pain Symptom Manage* 2018;55:1400–7.
  38. Jaramillo S, Hui D. End-of-Life care for undocumented immigrants with advanced cancer: documenting the undocumented. *J Pain Symptom Manage* 2016;51:784–8.
  39. Nuila R. Home: palliation for dying undocumented immigrants. *N Engl J Med* 2012;366:2047–8.
  40. Castro-Echeverry E, Kao LS, Robinson EK, et al. Relationship between documentation status and survival for medically underserved Hispanic breast cancer patients. *J Surg Res* 2013;180:284–9.
  41. Castañeda H. *Paradoxes of Providing Aid: NGOs, medicine and undocumented migration in Berlin, Germany*. Tucson, USA: The University of Arizona, Department of Anthropology, 2007.
  42. Coppola N, Alessio L, Gualdieri L, et al. Hepatitis B virus, hepatitis C virus and human immunodeficiency virus infection in undocumented migrants and refugees in southern Italy, January 2012 to June 2013. *Euro Surveill* 2015;20:30009.
  43. Bodenmann P, Vaucher P, Wolff H, et al. Screening for latent tuberculosis infection among undocumented immigrants in Swiss healthcare centres: a descriptive exploratory study. *BMC Infect Dis* 2009;9:34.
  44. Mylius M, Frewer A. Access to healthcare for undocumented migrants with communicable diseases in Germany: a quantitative study. *Eur J Public Health* 2015;25:582–6.
  45. Haldal E, Kuyvenhoven JV, Wares F, et al. Diagnosis and treatment of tuberculosis in undocumented migrants in low- or intermediate-incidence countries. *Int J Tuberc Lung Dis* 2008;12:878–88.
  46. European Centre for Disease Prevention and Control. HIV and migrants: monitoring implementation of the Dublin declaration on partnership to fight HIV/AIDS in Europe and central Asia: 2017 progress report. 2017 <https://ecdc.europa.eu/sites/portal/files/documents/HIV%20and%20migrants.pdf> (Accessed 04th Jul 2018).
  47. Deblonde J, Sasse A, Del Amo J, et al. Restricted access to antiretroviral treatment for undocumented migrants: a bottle neck to control the HIV epidemic in the EU/EEA. *BMC Public Health* 2015;15:1228.
  48. World Health Organization. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2016 <http://apps.who.int/iris/bitstream/handle/10665/246200/9789241511124-eng.pdf?sequence=1> (Accessed 11th Apr 2018).
  49. Médecins Sans Frontières. Experiences of Gömda in Sweden. Exclusion from health care for immigrants living without legal status. 2005 <https://lakareutangranser.se/sites/default/files/reportgomdaswedenen.pdf> (Accessed 04th Jul 2018).
  50. Biswas D, Kristiansen M, Krasnik A, et al. Access to healthcare and alternative health-seeking strategies among undocumented migrants in Denmark. *BMC Public Health* 2011;11:560.
  51. Priebe S, Matanov A, Barros H, et al. Mental health-care provision for marginalized groups across Europe: findings from the PROMO study. *Eur J Public Health* 2013;23:97–103.
  52. Teunissen E, van den Bosch L, van Bavel E, et al. Mental health problems in undocumented and documented migrants: a survey study. *Fam Pract* 2014;31:571–7.
  53. Teunissen E, Tsaparas A, Saridaki A, et al. Reporting mental health problems of undocumented migrants in greece: a qualitative exploration. *Eur J Gen Pract* 2016;22:119–25.
  54. Strech D, Synofzik M, Marckmann G. How physicians allocate scarce resources at the bedside: a systematic review of qualitative studies. *J Med Philos* 2008;33:80–99.
  55. Holmes SM. The clinical gaze in the practice of migrant health: mexican migrants in the United States. *Soc Sci Med* 2012;74:873–81.
  56. Huschke S. *Kranksein in der Illegalität: undokumentierte Lateinamerikaner/-innen in Berlin. Eine medizinethnologische Studie*. Bielefeld: transcript Verlag, 2014.
  57. Ticktin M, Ethics W. Ethics and politics meet: the violence of humanitarianism in France. *Am Ethnol* 2006;33:33–49.
  58. Torres-Cantero AM, Miguel AG, Gallardo C, et al. Health care provision for illegal migrants: may health policy make a difference? *Eur J Public Health* 2007;17:483–5.